

Improving communication with multiple sclerosis patients

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Multiple sclerosis (MS) is a chronic demyelinating disease affecting the CNS and is predominant in the young population aged 20-40 years. The awareness of patients and caregivers has risen to a new level as their scientific knowledge of chronic disorders has improved through the use of advancing communication technology such as the Internet and social media. Patients can easily access medical and scientific information on certain disorders through web browsing and search engines such as Yahoo, Google, and so forth. The interactions between patients and different patients' societies through Facebook and Twitter have provided additional information on the social impact of chronic diseases and allowed sharing experiences on how to deal medically with illnesses. Hence, the process of physician's communication with patients and their caregivers has to parallel the upward trend in patient's awareness and knowledge to allow the patient and the caregivers to articulate and discuss the information gathered from the web and social networking in a timely, scientific, and professional manner. The objective of this article is to discuss aspects of communication skills among neurologists and MS specialists that will improve patient-physician interaction; with more emphasis toward patients with MS.

Diagnostic phase. Uncertainty plays a major role in the diagnostic phase, especially when patients are being referred across different medical specialties. Some patients tend to seek second opinions to confirm the diagnosis, perhaps hoping for a non-chronic diagnosis. Patients may go through a phase of shock and denial after receiving the provisional diagnosis, which would change patients' short and long-term plans.

A questionnaire-based study conducted in patients with chronic disease found that networking and browsing were the most significant motivations for patients with MS.¹ Communication involves both receiving and giving information where different perspectives can be reconciled. The physician has the ability to direct the

first encounter and create a successful meeting using the following aspects of communication skills:

a) **Gesture:** Engagement is key to a successful relationship. Body language and eye contact are pillars when initiating an interaction.

b) **Effective listening:** Listening to reasons why patients seek doctors' opinions is crucial, since interrupting the patients may break the order of thinking resulting in patient frustration.

c) **Information and breaking "bad" news:** It is important to set the level of information that is given to the patients and caregivers at the first encounter. Any chronic diagnosis is usually considered "bad" by patients, so a stepped approach is advised. Patients and caregivers are interested in receiving the diagnosis, so hampering them with other information may not be effectively registered. Additional family members may be needed to be present when breaking "bad" news.

d) **Empathy:** Physicians are advised to be compassionate and empathic, as most patients are aware of the disability label and social stigma attached to the condition.

e) **Hope:** patients often seek medical opinions looking for a cure, so it is imperative that optimism should be dominating the final comments of the meeting. It is shown that greater hope is associated with better adjustment and coping.²

f) **Next meeting:** Physicians may ask patients to prepare and write down their questions and bring them to the next visit. It is preferred that patients are accompanied by family members to improve the registration of new facts and to provide support and empathy.

Transitional phase. After the initial visits, MS patients often accumulate vast knowledge of the disease characteristics such as symptoms, causes, treatments, and prognosis. Some of the information is scientific; some is based on others' experience, and some is not realistic, such as curing the disease. Physicians are expected to

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respond with some certainty given their expertise. The second encounter with the patient sets the stage for the long-term patient-physician relationship. The following aspects may help at the second physician-patient visit:

a) **Environment:** It is usually advised to have caregivers present at the meeting. Family members may help to retrieve some of the points discussed with the patient. The MS caregivers often experience more burden than non-MS caregivers, highlighting the need for the healthcare providers to recognize the social impact of the disease earlier so that appropriate measures can be implemented.³

b) **Clarification:** The doctor may start with what was understood by the patient in the previous meeting and ask whether there were any points that need clarification or further elaboration. The doctor may take a few minutes to update the patient on any returned results at this stage.

c) **Expansion:** The doctor may then start explaining the disease in details outlining the natural history of MS, causation, risk factors, what to expect in terms of symptoms, how to deal with ongoing symptoms, treatment options (pharmacological and non-pharmacological), prognostic factors, and the overall expected quality of life.

d) **Target:** The treating physicians should help in shaping a clear plan based on their scientific knowledge and expertise. Both the physician and patient may set a logical and feasible target to reach. For example, the doctor may say, "our objective is to keep you symptom free, working, and living independently". Patients' goals may be different than physicians perspectives depending on the age, educational level, and the social aspect. For example, patients goals may include the ability to finish school, to work, to raise a family, or to maintain a social relationship. Raising the expectation bar too high may be harmful to the patient as this may break their self-confidence.

e) **Control:** Patients often want to be involved in the process of decision-making since this may be the starting point for acceptance of their diseases. The treating physicians may list therapeutic options, may explain the benefits, and risk of each therapy, and may recommend certain treatments. Discussing these aspects in an interactive manner helps empower patients. Delaying the initiation of disease modifying therapies at this stage is preferable as patients may need some time to discuss different options with their family members, friends, and occasionally with family doctors.

f) **Common questions:** Certain questions with respect to disease aspects may enter the discussion. Thus, the treating physicians have to be prepared for such questions, which may be related to genetics, transmission to children, pregnancy and delivery,

and certain precautions such as direct sun, prolonged sauna exposure, exercise, diet and food restriction. The physician may take this opportunity to tell patients how to reach his/her office if the patient has any additional questions or develops new symptoms.

Management phase. Treatment decisions are considered a life's turning point to the patient, so the physician may need to re-confirm the patient's understanding. False expectations and perceived lack of efficacy are the main factors for non-adherence to medications. The natural history and the course of the disease may be addressed at this stage to point out the differences among MS patients in terms of genetic predisposition, relapses, accumulation of disabilities, and response to therapy. Certain clinical and radiological features at onset may predict the future disease course and these predictors may be useful for prognostication, and may guide the treatment plan. Some patients may progress faster and enter secondary progressive phases at earlier stages, while others may tend to have a benign course with less frequent relapses with a long interval between relapses and without residual disabilities. It is important to address the fact that a benign course is usually a retrospective consideration, which can only be confirmed with time.

a) **Outcomes:** The doctor should explain the scientific objectives of therapy; namely, to prevent relapses and progression, while pointing out other practical goals such as resuming daily activities and improving symptoms. Patient-reported outcomes have become important outcome measures that may be appealing to legislative authorities in the future.⁴ Patients with MS appear to be far more concerned with more intangible factors connected with their quality of life such as mental health and vitality instead of physical disability.

b) **Decision:** Once the patient and the treating physician agree on a specific management plan, the physician may discuss precautions, adverse events, and future monitoring processes. The MS nurse has a valuable role at this stage, especially with patients starting on injectable medications, which may need teaching and adaptation. The availability of nursing support helps the physicians to address non-urgent matters in their busy clinics.

c) **Alternative medicine:** MS specialists may be asked about the effectiveness of non-approved medications. Patients usually seek treatments, which offer the magic term of "cure". Emotions matter a great deal in the psychology of patients and caregivers, which may be the trigger for seeking alternative therapies. Skovgaard et al⁵ collected data from 3361 patients on the use of complimentary alternative medicine (CAM). They found that alternative medicine users were more

likely to be of female gender, 18-40 years of age, educated at bachelor level, or above, and had a high income compared with CAM non-users. Hence, the physician should be aware of the available CAMs and how to handle the discussion without being biased.

d) A multi-disciplinary team approach: Patients with MS may require the involvement of other specialties such as ophthalmology, urology, psychiatry, physical medicine, and rehabilitation given the wide range of symptoms and signs they may experience. Involving the social worker may help to clarify certain aspects of employment, social, and disability benefits. Some patients may need occupational or physical therapists as part of the multi-disciplinary team's approach to assist with their ongoing disabilities.

e) Scheduled visits: Ideally, the physician should evaluate the patient after 1-2 months of treatment initiation, and every 3-6 months thereafter. The following list provides a sample of different issues commonly discussed on follow-up visits: coping with the disease (acceptance, insecurity, social support); psychological aspect of the patient (anxiety, depression); quality of life and activities of daily living; employment and work-related issues; ongoing symptoms: fatigue, cognition, and bladder symptoms; reassurance about disease management; adverse events and adherence to medication; involvement of other members of the multi-disciplinary team; exercise, nutrition and smoking; immunization and travel; and pregnancy planning.

f) Unscheduled visits: Patients may call for urgent or unscheduled visits to discuss new symptoms (possible attacks) or urgent matters such as unexpected pregnancy or adverse events. The first major attack (relapse) that a patient experiences is often a challenge for the clinical relationship. The psychological impact of the attack is important, as this reminds the patient of the seriousness of the disease and possible future deterioration. Maintaining trust and confidence with a compassionate approach while dealing with a relapse is paramount to containing emotional and social vulnerability.

g) Electronic communication: Given the wide use of e-mails and other social networking such as LinkedIn and WhatsApp, physicians may be contacted by patients or caregivers with regards to new symptoms or certain unexpected issues such as medication adverse events, or decisions on future procedures (dental extraction, minor, or major surgeries) or even asking about research developments heard in the news, web, or through social media. In cases of suspected relapses, the development of unusual symptoms, or the emergence of unexpected side effects, it is important that the treating physician uses this method of communication to schedule an urgent visit to examine the patient and to address any urgent issue without raising the patient's fear and

anxiety feelings. E-mails and other methods of electronic communication may be valuable tools to the physician to address any minor issues, to educate patients, and to monitor adherence to specific medication, or treatment plans. Most physicians have busy clinics; thus, scheduling patients may not be an easy process. However, this should not discard the physician from evaluating patients when deemed necessary. It will not always be feasible to provide an opinion through e-mail given the limitation of the available information, as some important clinical information might be missing. Therefore, a phone call or an urgent appointment to a multi-disciplinary team member (clinical nurse) may be adequate to solve the ongoing issue.

In summary, effective communication between the patient and physician is crucial to the success of ongoing and future management. Empowering patients through education and sharing the decision-making process are the initial pathways toward disease acceptance and treatment adherence. Patient's knowledge and motivation supported by advancing communication technology have increased in the last decade. Physicians are advised to keep an open door policy with MS patients by allowing them to schedule visits when necessary to discuss important emerging disease aspects or to discuss ongoing concerns regarding the treatment plans. Patient-centered outcome measures have become valuable end-points in assessing the effectiveness of treatment and quality of life. The role of the healthcare professional is not limited to the modification of certain disease aspects, but is extended to support patients in assuming normal life in the community and in maintaining their daily activities in an environment of hope and optimism.

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